12-17-2011

Young Adults With Mental Illness in North San Diego County - YAMI

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December 17, 2011

Table of Contents

Needs Assessment

Studies show the onset of mental illness often occurs before or during the critical transition from youth to adulthood (ages 18-25 years) (Kessler et al, 2005). Illness symptoms, social stigma and stereotypes, along with the trauma of onset and diagnosis, can lead young adults with mental illness (YAMI) to isolate (Romer & Bock, 2008). This tendency to isolate severely affects the quality of life and potential for recovery of over 14,000 YAMI in San Diego's North County (San Diego Association of Governments, 2010; Substance Abuse and Mental Health Services Administration, 2010).

Target Population and Community

The target population for this research study is young adults ages 18-25 diagnosed with a serious mental illness (SMI) and living in northern San Diego County. This age range is consistent with Substance Abuse and Mental Health Services Administration's (SAMHSA) definition of a young adult. A SMI is a mental, behavioral, or emotional disorder that substantially interferes with or limits one or more major life activities (2008, National Institute of Mental Health). SMI diagnoses include schizophrenia; bipolar disorder; major depressive disorders; anxiety disorders (National Alliance of Mental Illness, 2009). According to the County of San Diego, Health and Human Services, Public Health Services, and Community Health Statistics Unit, North San Diego County encompasses the North Central, North Coastal, and North Inland regions (2010).

In North San Diego County, there are over 192,000 individuals between the ages of 18-25, and of this population, more than 14,000 (7.3%) have a SMI (San Diego Association of Governments, 2010; SAMHSA, 2010). Because YAMI often have more than one diagnosis, it is difficult to break down the population by disorder.

The majority of the young adults in northern San Diego County with a SMI are white, non-Hispanic (48%) and Hispanic (32%); Asians make up 11% of the target population and Blacks and individuals who identify as two or more races make up 5% of the population (2009, County of San Diego, HHSA, Public Health Services, Community Health Statistics Unit).

On a national level, 29.6% of the 18-24 year old population in general does not have health insurance (National Center for Health Statistics, 2011). Using this finding, it can be estimated that 57,000 young adults in North San Diego County are without health insurance. Additionally, according to national research, the cost of health care is the most frequently cited reason (42.5%) by adults over the age of 18 for not treating mental health symptoms (SAMHSA, 2010). It is estimated that approximately 83,000 18-25 SMI households in North San Diego County have an annual incomes of less than $45,000 (2009, County of San Diego, HHSA, Public Health Services, Community Health Statistics Unit), which demonstrates a financial limitation for individuals seeking costly treatment.

Challenges in Mental Health Treatment for YAMI

Young adults are navigating a life stage in which they are trying to establish independence, and a mental health diagnosis can interfere (Arnett, 1997). For example, healthy young adults generally attend and finish college and/or begin careers during this time period, and establish their first serious romantic relationships (Rosenberg, 2008). Often, the onset of serious mental illness causes a "psychological break" in which the YAMI's brain simply stops working as it did before. This "break" can be a traumatic experience, one that forces the YAMI to retreat or isolate from the world, which may suddenly seem unmanageable and frightening (Kessler, et al. 2011). This isolation is a barrier to normal life activities and consistent medical treatment. It

then becomes more difficult for the YAMI to re-engage with the world, perpetuating a cycle that further ingrains isolation (Romer & Bock, 2008).

Exacerbating the isolation is the stigma that accompanies mental illness (Romer, Bock, 2008). Unlike other diseases (e.g., people living with cancer), the isolating nature of those with mental illness does not naturally foster a community of support (Rosenberg, 2008). This, combined with a deficit of public education around mental health can also prevent YAMI from maintaining friendships, consistently complying with treatment and continuing on the path to recovery (Romer, Bock, 2008). Images portrayed in the media often reinforce negative stereotypes of mental health symptoms (Jivanjee, Kruzich, Gordon, 2008). These stereotypes fuel the stigma felt by YAMI, making them feel less accepted and less a part of the community (Romer, Bock, 2008; Rosenberg, 2008). This stigma fosters isolation and loneliness, and can stand in the way of close, supportive relationships when they are most needed (Jivanjee, Kruzich, Gordon, 2008).

Societal Implications

The challenges that YAMI face have implications for the larger society. The majority of people with a severe mental illness do not have paid employment (Rice, Howard, Leese, Jarrett, Thornicroft, 2009). Of young adults 18-25 residing in northern San Diego County, approximately 20,000 individuals who are employable are unemployed (2011, United States Department of Labor, Bureau of Labor Statistics). Unemployment causes further dependence on entitlement programs and adds an additional barrier to accessing health care.

Isolation can also lead to substance abuse, homelessness, and possible incarceration; this is particularly true for YAMI who are poor and rely solely on public services (Rosenberg, 2008; Romer, Bock, 2008). Twenty-two percent of young adults in the United States are struggling

with substance abuse; many of those have a mental illness (Gayman, Cuddeback, Morrissey, 2011). Alcohol abuse alone cost United States tax payers $148 billion a year (Gayman, Cuddeback, Morrissey, 2011). The cost to those with a mental illness goes beyond numbers. When substance dependence or abuse is present alongside a mental illness, an individual is twice as likely to attempt suicide than one who avoids alcohol and drugs (SAMHSA, 2009).

Focus Groups and Key Informant Interviews

Two focus groups were conducted to collect data. One consisted of four YAMI and a twenty-six year old, all members of Impact Young Adults (IYA), an organization for young adults with a mental illness, run by other YAMI (peers), that provides social activities, mentoring, and leadership opportunities. The other focus group was made up of two YAMI who are not members of IYA and who reside in North County. Mental health diagnoses of the focus group participants included attention deficit hyperactive disorder (ADHD), obsessive-compulsive disorder (OCD), depression, bipolar disorder, schizophrenia, and schizoaffective disorder.

The isolating nature of YAMI made it extremely difficult to identify potential focus group participants. For this reason, there are inherent biases associated with both focus groups. All participants had some connection to the lead researcher on the University of San Diego (USD) research team. Each individual was medication and treatment compliant, identified as white, came from a middle-class background with positive parental support, and had health insurance. The research team went outside the operational definition of "young adult" and included a twenty-six year old. This was an attempt to diversify the gender within the group, however despite this effort, all other participants in that focus group were male. Key findings and emerging themes included:

Both groups felt there was very little education for the general population (specifically their age group) regarding mental health and mental illnesses. Participants agreed this lack of education added to the stigma that accompanies a mental health diagnosis, and felt uncomfortable trusting others with the information. One group brought up the casual use of mental health diagnoses as mood descriptors used by the public at large, such as "I feel so ADD today" or, "she is acting so bipolar." Some participants took offense to the common use of these terms by those without a diagnosis, saying it made their struggles seem trivial. Currently, a county wide campaign and other programs are addressing this concern, and the focus group comments reinforce the need of community acceptance. Please see the Logic Model on page 18 for more information.

In both groups, individuals experienced bullying as a result of their mental illness. One participant with schizophrenia was asked if she was going to chop classmates into pieces. Other participants felt abandoned and betrayed by those they considered friends once their diagnosis was revealed. The majority of participants identified only one close friend (if any) and expressed challenges in managing a group of friends and their illness. Participants from both groups expressed difficulty finding the "right" medications and the "right" professionals to help manage their symptoms.

Researchers conducted key informant interviews with: a mental health service provider serving the YAMI population, a parent of a YAMI, the Impact Young Adults (IYA) co-president who is a subject matter expert, a current IYA member, and an individual diagnosed as a young adult who was not involved with any peer-led program. Similar to the focus groups, interview participants were extremely difficult to identify and meet with. Many potential interviewees were not yet comfortable speaking about their diagnoses and others did not follow through after

agreeing to an interview. Due to these limitations, researchers interviewed two individuals slightly over the age of twenty-five, both of whom were diagnosed as young adults. One lives outside of North San Diego County.

Interviewees brought up three overarching themes: the self-isolation/lonliness of YAMI, the cost of treatment, and the importance of socialization. YAMI and their families are extremely isolated and find it difficult to build and maintain relationships. Interviewees said the stigma of having a mental illness and the lack of societal support had prevented them from speaking to anyone, even close friends and family members, about their diagnosis. Treatment of a mental illness can include medications, therapists, psychiatrists, other medical specialists and support groups. Interviews revealed the cost of treatment as a burden to YAMI and their families. The parent of a YAMI who was interviewed spent over $350,000 for in- and out-patient treatment in one year; another interviewee shared that therapy was so costly it prevented her from receiving other treatment services.

Many of the interviewed participants mentioned the importance of socialization for YAMI. The mental health provider stated that socialization is a “must” for this population and another participant said socialization helps YAMI feel like they belong. One outlying statement in the interviews came from the mental health provider, who claimed to be unaware of any unmet needs of YAMI or their supporters. In addition, when the researchers were speaking with other providers to identify focus group and interview participants, many providers openly expressed their lack of confidence in the response of YAMIs. This points to providers’ lack of awareness, understanding, and confidence in their target population.

The unique factors of the young adult life stage, combined with the trauma of the onset of mental illness and the stigma around mental health, leave YAMI in a particularly vulnerable

state. Focus group participants and key informants identified self-isolation/lonliness and stigma as barriers to building a network of support and a social life, two factors that contribute to recovery and wellness. Primary data findings support a program design that offers social opportunities and peer outreach for YAMI. Increased social engagement with other YAMI (peers) may help break the cycle of isolation and lonliness for some YAMI and foster community among them.

Program Design

Literature Review

In preparation for the program design, a literature review was conducted based on common themes that arose in the primary data collection (see Appendix A). In order to reflect the four program activities, the USD research team chose to focus the literature review on the following four categories: 1) peer-led support structure: 2) social gatherings 3) leadership training and 4) peer to peer outreach. Please refer to the Workplan, Appendix C.

Peer-Led Support Structure.

Even when YAMI are in a state of isolation, they still express a need for social relationships (Davidson, et al., 2004). In an effort to combat the tendency to isolate and assist in social engagement, a new movement emerged in the 1990's with the goal to engage and empower individuals with a mental illness of all ages by having them run their own support organizations (Davidson, Chinman, Sells, & Rowe, 2006). Since then, these "peer-led" or "consumer-run" health services have gained acceptance within the mental health community and become the subject of research.

The remaining literature relates to the general adult population (those over the age of 18) due to lack of age specific studies available. Solomon (2004) surveys current literature to define

the principles of peer support and share evidence of its efficacy. This article defines peer support and identifies various types of services as: self-help groups; Internet support groups; peer-delivered services; peer-led or operated services; peer partnerships; and peer employees (Solomon, 2004). Solomon (2004) outlines the psychosocial processes that underlie peer support, and refers to existing literature to recount the benefits of peer support services for consumers, providers and the mental health delivery system. The article also examines "ingredients" of service and characteristics of peer providers that support evidence of effectiveness (e.g. voluntary, in-recovery, not a substance abuser, etc.) (Solomon, 2004).

Doughty and Tse (2011) also sought to determine the effectiveness of consumer-run mental health services. After defining inclusion criteria, researchers appraised 29 studies conducted in high-income countries. Patient outcomes of traditional mental health services were compared to those of consumer-run health services (Doughty & Tse, 2011). Across all studies, researchers found outcomes were equally positive for clients regardless of whether the service was peer provided. However, employment was an area where consumer-run mental health systems appeared to be more effective than traditional ones. By involving consumers in the delivery of their own services, consumer-run programs provided opportunities for employment, and a better quality of service to clients (Doughty & Tse, 2011). The studies reviewed by Doughty and Tse (2011) all took place in high-income countries, limiting the ability of the study to be generalized. The study authors recommend further research and note that when building a consumer-run intervention, consumers should determine the services to be developed (Doughty & Tse, 2011).

Schurr and Rogers (2009) used interviews and focus groups to examine motivations behind client participation and retention in peer-led programs. The participants were chosen

from one of the peer-led programs located in a large mid-western city. The median age of the interviewees was 40 years, eight participants were male, most were high school graduates, four had not finished high school and one had some schooling beyond high school (Schurr & Rogers, 2009). Patients felt the benefits found in the peer-led program could not be found in a traditional health care setting, and this was their primary motivation for continued engagement. The benefits included social relationship development and interaction with others, which helped the patients put problems into perspective, feel accepted, and increase their problem solving skills (Schurr & Rogers, 2009). The majority of study participants felt less judged at the peer-led program center and staff members reported additional benefits (Schurr & Rogers, 2009). All participants were already engaged in an empowerment program, indicating a bias in the study. Also, findings would have been more conclusive if more than one program had been studied. The study authors suggest more empirical research as these types of programs rise in popularity (Schurr & Rogers, 2009).

Moran et al. (2011) studied 31 individuals with mental illness who provide peer support within consumer-run mental health programs. The purpose of the study was to explore how "working as a peer provider can enhance personal recovery" (Moran et al., 2011, p. 1). Study participants were recruited via electronic communication and word of mouth. The criteria for the first round required a minimum of two years employment experience with a peer provider and a diagnosis of a serious mental illness. The second round broadened to include peer providers with less experience (Moran et al., 2011). The median age for participants was 44.6 years, 55% were female, 97 % identified at white, 64% were single, 61% held a bachelor's degree or higher, and work experience varied (Moran et al., 2011). Semi-structured, face-to-face interviews were conducted, and data was qualitatively analyzed using a grounded theory approach. The grounded

theory approach is one where the researcher utilizes the coding process as an analytic tool itself, not just as part of the overall data analysis process (Moran et al., 2011). The study found recovery benefits for peer providers that spanned across five areas: foundational, emotional, spiritual, social, and occupational (Moran et al., 2011). The non-representative sample of this study limits its ability to be generalized, and the authors recommend future research be done with every attempt to diversify the sample (Moran et al., 2011).

Social Gatherings.

While the previous articles show peer-led support can help combat isolation/lonliness, other research indicates that having a larger social network, both with peers and non-peers, is related to ongoing recovery (Corrigan & Phelan, 2004; Hendryx, Green, & Perrin, 2009). Research also indicates that participation in activities, regardless of type, can be correlated to factors associated with ongoing recovery, such as engagement with others (Hendryx, Green, & Perrin, 2009).

Corrigan and Phelan's study (2004) did not involve an intervention, but rather sought to compare objective and subjective measures used to determine the relationship between social support and ongoing recovery from a mental illness. Study authors used the baseline assessment of 1,824 individuals with a DSM-IV, Axis I diagnosis (clinical disorders such as schizophrenia, bipolar disorder, depression, etc.) consistent with serious mental illnesses and a significant functional disability that resulted from the mental illness (Corrigan & Phelan, 2004). All participants completed the Recovery Assessment Scale (RAS), which assessed factors such as personal confidence, goal orientation, and ability to manage symptoms. One hundred and seventy-six individuals completed the RAS, a semi-structured interview, and Social Network Scale to assess the size of their overall social network and its effect on recovery (Corrigan &

Phelan, 2004). The authors found that individuals with a serious mental illness who reported larger numbers of people in their networks were also more likely to report such aspects of recovery as "greater hope" and "being more oriented towards goals and success" (Corrigan & Phelan, 2004). In examining the impact of sub-networks, some recovery factors were found to be associated with the number of people in the friend and professional health networks, but not the family networks. While this study shows a correlation between larger social networks and ongoing recovery, the directionality of these relationships is not clear. Future research is recommended to determine whether better social support leads to ongoing recovery, or if people who consider themselves to be in the process of recovery are able to manage larger networks. The authors recommend a multi-panel design, a research design that reviews participant progress in different panels of time (e.g., 0-1 year, 1-2 years, 2-3 years, etc.), to continue this research (Corrigan & Phelan, 2004).

Hendryx, Green and Perrin (2009) also explored the relationship between social support and recovery with a specific focus on participation in activities. Inclusion criteria included a diagnosis (for a minimum of 12 months) of schizophrenia, schizoaffective disorder, bipolar disorder, or affective psychosis; at least 12 prior months of health plan membership; a minimum age of 16 years; and plans to stay in the local area for at least 12 months. Study participants included 92 women (52%) and 85 men (48%). The average age of participants at baseline was 49 years, with a range from 16 to 84 years. Approximately 94% identified as white. The total number of participants was 177, but missing data on items of interest reduced the sample to 153 for the current study (Hendryx, Green & Perrin, 2009). Study authors employed mixed methods in this longitudinal, exploratory study. They collected baseline, quantitative information from a questionnaire that they then linked to health records of service use and diagnosis (Hendryx,

Green & Perrin, 2009). Results showed that social network size and greater involvement in a wide range of activities both related to better recovery. The involvement in activities, regardless of activity type, was found to be particularly advantageous when levels of social support were reported as lower (Hendryx, Green & Perrin, 2009). These findings suggest that a clinician's encouragement towards patient participation in social engagement and activities could aid in ongoing recovery. Findings also suggest that a patient's pursuit activities could be a "viable approach to taking control of the recovery process" (Hendryx, Green & Perrin, 2009).

Leadership Training.

While there is limited research examining the effects of leadership skills on individuals challenged with a mental health diagnosis, the USD researchers were able to find one highly relevant article in support of this activity. Hess, Clapper, Hoekstra & Gibson (2001) examined the effects of leadership training to adults with a SMI and their families. The study included 160 participants; 58% consisted of consumers and 42% of family members of an individual with a SMI. Twenty-four percent of participants had a bipolar diagnosis, 8% suffered from depression, 17% had a diagnosis of schizophrenia, 9% included other diagnoses, and 42% were not reported because they are family members. The majority of participants identified as white, but there was a large representation of the Native American population because of the region of Idaho in which the study was conducted, and the author's focus. All participants were under 70 years of age, with approximately half under the age of 40 years (Hess, Clapper, Hoekstra & Gibson, 2001).

Participants in this study attended at least one leadership academy that spanned two and a half days' time. Leadership and advocacy skills were taught using workbooks, group discussions, small group exercises and role-playing. A social event was held on the evening of the first day that included snacks and entertainment, all organized by participants (Hess, Clapper, Hoekstra &

Gibson, 2001). Graduates were invited to apply to teach the fourth and fifth sessions of the academy. All previous graduates could choose to move to an advanced training track. An average of 28 graduates participated in the advanced training track and received additional training in public speaking, media relations, fundraising techniques and online community networking. Post-academy, graduates were given the opportunity to participate in conference calls every 6-8 weeks with other graduates to discuss progress (Hess, Clapper, Hoekstra & Gibson, 2001).

The study authors established clear outcome goals and measures based around advocacy actions. In just over two years time, participants initiated 1,345 advocacy actions that included issues surrounding stigma and consumer rights. Of these actions, 400 achieved outcomes. At the six-month and one year follow-up post-academy, Hess, Clapper, Hoekstra & Gibson (2001) found that 68% of participants were still involved in advocacy. Participants also completed a written survey on their opinions of the academy. Seventy-nine percent to 93% of participants reported that the leadership academy had a positive impact on advocacy efforts and sense of empowerment and 66% considered the academy to be very useful. Participants reported networking and support as the most valuable aspects of the intervention. The study authors suggest future research to support the leadership and advocacy training for individuals with and SMI (Hess, Clapper, Hoekstra & Gibson, 2001).

Community Outreach.

When reviewing the literature focused on YAMIs, a theme that appears is the difficulty in reaching, recruiting, and retaining this population (Jivanjee, Kruzich & Gordon, 2008; Moran et al., 2011; Schurr and Rogers, 2009). There is a range of techniques used to identify and engage

challenging cohorts to participate in research studies. A review of the most relevant to the YAMI population is discussed below.

Jivanjee, Kruzich and Gordon (2008) recruited 59 YAMI from schools, colleges and alternative educational programs. They enlisted organizations that provided youth employment opportunities, as well as agencies that provided assistance to homeless and gay, lesbian, bisexual, transgender and queer (GLBTQ) youth. In addition, parents and family members of YAMI were recruited from family support organizations (Jivanjee, Kruzich & Gordon, 2008). Researchers used local contacts within these organizations to help distribute brochures and fliers, and send out electronic invitations. A total of twenty focus groups were conducted; twelve comprised of YAMI, and the other eight comprised of parents of YAMI). The researchers' use of family members and youth-focused organizations has potential as an effective strategy for recruitment of members of the YAMI population.

When seeking a group of adults with a serious mental illness residing in the community and receiving outpatient care, Davidson et al (2004) recruited at state-run health care centers in fourteen different cities in Connecticut. All participants had been referred to the study by clinicians at the various centers. After initial recruitment, patients were then divided into three groups, with each group receiving varying degrees of the intervention. All groups received a stipend as part of the intervention, and all groups indicated overall improvement over time (Davidson et al., 2004). The use of stipends or other incentives to attract study participants merits consideration.

Some researchers have achieved recruitment success with this population by utilizing the Internet. Van Voorhees et al. (2005) recruited 10,962 persons, aged 16 to 29 years old, who demonstrated moderate or greater likelihood of having major depression after participating in an

online screening. Researchers used an Internet survey to test beliefs and attitudes surrounding the acceptance (or lack of acceptance) around a mental health diagnosis. The data from the Internet sample was compared to a sample of individuals receiving primary health care who had taken the same survey (Van Voorhees et al., 2005). Even though the Internet sample had a higher proportion of white males and a larger proportion of non-primary care users, it still points to the success of recruitment of large numbers of young people through online methods.

Individuals with mental illness are one of many populations that pose a challenge to recruit and retain for research studies. Sadler et al. (2010) propose an adaptation of snowball sampling as a way to recruit hard to reach populations in a culturally sensitive manner. The authors provide a brief definition of snowball sampling, which involves a multi-stage process to recruit participants by tracing them through other participants (Sadler, et al., 2010). Although snowball sampling is not based in probability and therefore does not produce a random sample of the population, it is a successful strategy for gathering difficult to reach populations.

Similar to Jivanjee, Kruzich and Gordon (2008), Sadler et al (2010) recommend outreach to numerous sources including: individuals; formal and informal group leaders; business and social guilds; membership lists and phone directories. Personal communication with stakeholders in the outreach community is presented as the first step to reach isolated subgroups. Health fairs are also recommended as places to identify these groups and individuals. Sadler et al. (2010), note success has been achieved by utilizing the power or prestige of indirect sources. For example, placing brochures at church implies the church and its elders are supportive of the study, so members of a parish are more apt to participate (Sadler, et al., 2005). The article closes with a brief discussion of the emergence of social networking sites. These sites are a promising

addition to recruitment tactics, however researchers need to stay abreast of international human subject regulations regarding privacy when using these tools (Sadler, et al., 2005).

Purpose of Study

As outlined above, research indicates there is a relationship between peer-led mental health services and factors of recovery, and some studies have indicated this approach could be particularly beneficial for YAMI (Romer & Bock, 2008). This proposed study will examine whether increased social interaction and leadership skills provided by a peer-led organization contribute to a decrease in isolation/lonliness. A decrease in isolation/lonliness is one component that will assist ongoing recovery for YAMI (see Program Design Narrative). Data on the relationship between peer-to-peer engagement and lonliness for YAMI will be collected and analyzed. The intervention in this proposed study would address the gap in the current literature on YAMI, while creating a new hub for peer engagement for YAMI in northern San Diego County.

Logic Model Matrix

Please refer to Appendix B.

Program Design Narrative

Based on a review of the literature and an assessment of the needs of YAMI, the USD researcher team proposes a program to engage YAMI in a peer-led support structure that will provide social gatherings, peer-to-peer outreach and leadership training over an eighteen-month period. These interventions are designed to achieve the hypothesized outcome of a decrease in loneliness that will lead to an increased ability to maintain recovery. The researchers utilized the five factors of recovery measured in the Recovery Assessment Scale to define “ongoing

recovery," and inform the program design. These factors are: personal confidence and hope; willingness to ask for help; goal and success orientation; reliance on others; and not being dominated by symptoms (Corrigan & Phelan, 2004). In addition, it is the hope of the USD team that this study will further contribute to the body of research about the benefits of socialization and peer engagement for the YAMI cohort.

Methodology

Research Design.

The USD research team is proposing a quasi-experimental study design to test whether the engagement of YAMI in the following intervention activities will decrease isolation/lonliness over an eighteen-month period: 1) social gatherings 2) peer-to-peer community outreach 3) leadership training 4) peer driven structure (see Appendix C). Since this study aims to identify a relationship between loneliness and interventions that involve social interaction with peer YAMI, an experimental design is preferred. However, research and experience indicates this population is difficult to reach and retain (Jivanjee, Kruzich & Gordon, 2008), and random selection of participants is not practical. Therefore, a quasi-experimental design is most appropriate.

Study Sites, Participant Recruitment and Selection.

The USD researcher team will use a variety of tactics to recruit participants, similar to the strategies stated in the literature review above. Study participation information will be available in at least twenty locations in northern San Diego County where YAMIs may be present, including college campuses, service areas, youth employment sites, family support organizations, health fairs, and religious sites. In addition, potential participants will be identified through existing relationships with service providers, parents, and YAMIs; social media; word of mouth; and personal recruitment. In order to qualify for study participation, each YAMI must be actively

involved in mental health treatment. This program design is meant to supplement medical treatment for YAMI.

Once 75 YAMI are identified through participant recruitment, they will be screened to ensure that their diagnosis falls within the definition of a SMI, they live in northern San Diego County, they are between the ages of 18-25, they are willing to participate in an eighteen month study, they are currently receiving mental health treatment, and gauge their current level of social engagement. Of the 75 YAMI identified, at least 50 YAMI will be selected for the study. Twenty-five participants will be randomly assigned to the experimental group and the other half of the YAMI participants will be assigned to the control group. Based on the USD research team's experience in attracting focus group participants during the primary data collection phase, the team is prepared for 60% to leave over the course of the study. This will leave a remaining 20 participants for the entire length of the study. All participants will receive a pre-assessment to measure their loneliness and current level of recovery. Locations for the administration of the initial survey are to be determined, but will most likely be some of the organizations assisting with the recruitment.

Staff Training.

To effectively work with this underserved population, the USD research team and IYA members participating in the research will receive special training. The researchers will partner with specialists, utilize cultural mediators to access this isolated population, and use resources aimed at YAMI or resources to which YAMI are likely to respond (e.g. social media). In addition, researchers will be educated on the unique cultural norms of this population including knowledge and understanding of specific diagnoses, treatment options and modalities, people-first language (such as saying "the girl who has bipolar disorder" versus "the girl is bipolar"),

and the population's sensitivity to other words and behaviors. YAMI will act as training consultants when possible. With cultural training, researchers will be more likely to gain respect and trust with participants and thus, effectively encourage their participation in the study. In addition, the researchers will be trained in community organizing. A key outcome of this program relies on the ability of the researchers to encourage, guide, and coach intervention participants in forming a new, peer-led group, without taking on the leadership role.

Intervention Protocol.

In the experimental group, the interventions include participating in a peer-led support structure, social gatherings, leadership training, and peer-to-peer community outreach. Participants will first attend a leadership training, which will offer participants a forum to meet other participants and gain leadership skills. Afterwards, participants will be encouraged to identify and plan various social gatherings; self-organize a leadership committee of participants, the start of creating a peer-led support structure; and outreach to other peers.

Though the USD research team believes all YAMI who are interested in participating in the intervention deserve to do so, a control group is essential. The control group will consist of individuals who are only receiving traditional, medical treatment to treat their illness. At the end of the study, all participants will complete a post assessment to measure loneliness and recovery. The experimental group will also be surveyed on how often they participated in social activities (with any individual or group). Post study, the control group will be offered the full intervention. Please refer to the Research Design Outline, Appendix D.

Social Marketing Plan

The USD research team is proposing a multi-pronged social marketing campaign, which will address unique aspects of the target population, including age, desire for acceptance and

belonging, and isolation/lonliness. Like those facing addiction or homelessness, YAMI are notoriously difficult to reach. The very reason they need to be engaged often makes reaching them a difficult task. This social marketing approach is crafted with these challenges in mind.

Target Population (Audience Segmentation)

The target population for this campaign is young adults ages 18-25 diagnosed with a serious mental illness [SMI]) over 14,000 of which reside in Northern San Diego County (SAMHSA, 2010). The majority is white, non-Hispanic (48%) and Hispanic (32%). The Asian population makes up 11% and individuals who identify as Black or multiracial make up 5% of the population (2009, County of San Diego, HHSA, Public Health Services, Community Health Statistics Unit). Slightly over half of the target population is male (SANDAG, 2011).

Within this population, the target will be YAMI who are engaged in mental health treatment, yet still experiencing social isolation/lonliness. Those in treatment will be targeted first due to their increased likelihood of response, and the limited resources available. Once the proposed program reaches capacity, YAMI who are actively involved will be well positioned to reach out to those who remain isolated. While the friends and family of YAMI are a critical part of their support system, the focus of this social marketing campaign is squarely on the YAMI population.

Product

The primary product being offered is a positive social experience and opportunities for personal connection with peers in a safe and non-threatening setting. The product will be delivered through a peer-led support structure, social gatherings, leadership training, and peer to peer community outreach. This product is simply packaged as a social group created by YAMI,

for YAMI. Ultimately, the program offers participants a sense of belonging.

Price

Since effective public education about mental illness has been limited, and stigma around mental illness is prevalent, the admission of a SMI comes with a risk of judgment. The judgment may be accompanied by fear, or the dismissal of a YAMI's value, particularly from peers. While engaging in the study means primarily interacting with other YAMI, the person in isolation may still feel there is a risk of being seen as "crazy," "dangerous," or "weird" (focus group, October 29, 2011). There will be a financial cost associated with attending social events, as well as the cost of transportation to and from these events. Low to no-cost events will be offered in an effort to overcome this potential barrier, as well as subsidizing for more expensive experiences such as live theater and theme parks. Participants will be encouraged to carpool and ride-share to limit transportation costs.

Place

In order to serve YAMI throughout the large area of North County, meetings and social events will be held in different locations. The research team will identify places and community centers at which YAMI naturally gather, such as college campuses, coffee shops, music clubs, local churches, synagogues, masjids and temples. These locations will also serve as hubs for promotional materials.

Promotion

Based on data gathered from focus groups and the experience of Impact Young Adults, a successful approach with this population is to not be overt about mental illness. YAMI are

seeking acceptance and want to feel like part of the mainstream population, they do not want to be defined by their illness. The primary message developed for this campaign's promotional materials is "we are more". The notion "we are more than our illness" normalizes the individual experience, and places each person in the context of a broader community. The message is crafted to promote engagement among the YAMI community. However, there is a secondary goal for the general population: to raise awareness of mental illness and break down stereotypes. In order to build identification, and to encourage YAMI to see themselves as the audience for the campaign, images of young people will be central to the look of the campaign. Local celebrities may be engaged to participate, as well. An excellent example of this type of approach can be seen in the popular "It Gets Better Project".

The promotional message will be communicated through posters placed in locations listed above, as well as public transportation centers and buses. Postcards will be distributed at coffee houses and music clubs, cause walks and health fairs. All print promotion will be tagged with a QR code leading to the campaign's website. YAMI are tech-savvy, and the campaign will also rely on a significant online presence. Ads can be purchased inexpensively on popular music sites like Pandora and Spotify, and will lead back to the website. A Facebook page will serve as a platform to post event updates, build online community, and share promotional videos. Other nonprofits can help cross-promote on their organizational websites, providing additional points of entry and reinforcement of the message. Young people are generally interested in music, and there is the potential to use concerts as an outreach and organizing tool, much like the anti-stigma mental health organization "To Write Love on Her Arms" has done.

All promotion will have a call to action, whether it's scanning a QR code, "liking" on Facebook, or watching a video. Ultimately, these initial actions might lead to engaging with the

YAMI community in person at a social event. With multiple touch points at popular North County locations and online, there is an increased likelihood of reach, visibility and retention.

Evaluation Plan

Evaluation Design

The evaluation design contains both outcome and process objectives with corresponding measures for evaluation. These qualitative and quantitative measures will provide data for analysis, which will determine the effectiveness of the intervention and the potential for replication. Demographic data, and behavioral data that will assess loneliness and the state of recovery will be included. These measurements will be administered on a strict timeline, as noted in the attached Workplan. Professional evaluators will provide training in the administration and collection of measurement instruments, oversee the evaluation process, and analyze data. The results of this evaluation will not only determine the intervention's success, but will also inform improvements for the future.

Evaluation Measures

There is a wide variety of instruments available to measure aspects of mental health. Three evaluation instruments are included in this design based on the proposed outcomes; intervention activity goals; validity and reliability; length; ease of use; and clarity. The first instrument will measure demographics, the second will measure a decrease in loneliness and the third will measure an individual's status of recovery.

Demographic Instruments.

Demographic information will be collected using questions adapted from the U.S. Census Bureau's American Community Survey (ACS). The ACS contains over 100 questions and is

available online. It is important to note that the USD research team has chosen to adapt a new version of the survey rather than use the original. The original survey provides space for information for up to twelve people in an individual's household. The USD research team is committed to making the evaluation process as stress-free as possible for the YAMI population, therefore the adapted questionnaire will focus only on items relating to the individual taking the survey, eliminating survey questions that pertain to other household members. Because only basic demographic information is needed, this will be sufficient. This adapted questionnaire will supplement the two behavior evaluation measures, which do not include demographic items.

To minimize measurement error, the ACS pretests and revises new versions prior to nationwide use, and the survey has been tested for reliability and validity (U.S. Census Bureau, 2009). ACS is a questionnaire design that reflects accepted principles of respondent friendliness and navigation; and includes a questionnaire instruction booklet providing additional information on how to interpret and respond to specific questions (U.S. Census Bureau, 2009). To ensure the adapted version maintains this standard, the USD research team and evaluation professionals will test the shortened ACS with YAMI prior to the start of the program. The format used in the original ACS will be maintained, and additional instructions on the adapted survey will be provided to help clarify interpretation of specific items.

Behavior Instruments.

The UCLA Loneliness Scale (Version 3) will be administered to participants to evaluate a decrease in loneliness at the end of the study. This 20-item self-rated measure reflects how lonely individuals describe their experience, using a 4-point Likert scale (Russell, 1996). The UCLA Loneliness Scale (Version 3) is available to use free of charge when properly cited. The tool is available within the text of Russell's "UCLA Loneliness Scale (Version 3): Reliability,

Validity, and Factor Structure (1996)", and has been tested for reliability and validity. The scale has good reliability (r=0.92) and strong validity when compared to similar tools measuring loneliness, including the NYU Loneliness Scale and the Differential Loneliness Scale (Russell, 1996).

This scale was selected for the program because it has been tested with populations in a similar age range and geographic region as YAMI in northern San Diego County. Adolescents (12-17), young adults (18-21), and adults (22-65) have been studied using the UCLA Loneliness Scale (Mahon, Yarcheski, & Yarcheski, 1995; Russell, 1996), and many studies using the scale focused on college age students. The UCLA Loneliness Scale has also been tested with populations in southern California. In at least two studies (Mahon, Yarcheski, & Yarcheski, 1995; Russell, 1996), participants resided in Los Angeles County, a county that relatively has a similar young adult population who may share similar beliefs and lifestyles. There are limitations of the UCLA Loneliness Scale: research shows consistent patterns of responding as a function of time, wording and the fact that scores are not normally distributed, may affect the result of statistical tests (Russell, 1996).

The Recovery Assessment Scale (RAS) will also be administered to measure a participant's level of recovery. This 41-item self-rated measure reflects a participant's recovery by assessing 5 recovery factors: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and not dominated by symptoms (Andresen, 2010). Like the UCLA Loneliness Scale (Version 3), this tool has good validity and reliability; was tested on populations similar to YAMI residing in northern San Diego County (Corrigan, Giffort, Rashid, Leary & Okeke, 1999); and may be used for free when properly cited (Ohio Coordination Center for Integrating Care, 2010).

The USD research team recommends further study of these measures on the YAMI population. There are a number of assumptions about what increases the number of surveys completed by YAMI's (such as the use of color and design in the survey, and the way it is administered) but this has not been officially documented.

Evaluation Methods

Studies show that having participants complete surveys in person improves response rates (Corrigan, Giffort, Rashid, Leary & Okeke, 1999). The ACS, UCLA Loneliness Scale and the RAS will be administered in person with iPads, to allow the surveys to be taken online. As noted, YAMI are comfortable using technology. It is the USD research team's hope that the use of iPads will increase participants' interest in completing each of the evaluation measures.

A staff member will be present during administration to address questions. Many YAMI have cognitive processing limits as a result of their SMI, and may need assistance and clarification in order to complete the measurement tool(s). To ensure survey answers are not affected, the staff member will be professionally trained on how to answer clarifying questions consistently.

The surveys will be programmed into SurveyMonkey.com, a reputable survey creation tool. SurveyMonkey.com is free to use and provides researchers the ability to format the surveys and evaluations consistent to their original layout. In addition, SurveyMonkey.com uploads survey results to a Microsoft Excel format, which will be used to analyze the program evaluations. The use of Excel will be appropriate for the amount of data and number of participants (under 50). As the program grows, a more sophisticated data analysis system will be needed. To meet this need, the program staff will look for opportunities to partner with local

universities that utilize SPSS or local mental health organizations that use the San Diego County mental health database, Anasazi.

Closing

Study Strengths.

This study and program design is informed by valid and reliable empirical research studies. Additional study strengths include the use of baseline measures, and a control group to evaluate the effectiveness of the intervention. The evaluation tools have been tested for validity and reliability on similar populations and are cited in numerous previous studies. The creation of this study is concurrent with a growing awareness of mental health issues in the medical field, media and society, which make it particularly relevant. Because of the age of the target population, this study provides early intervention, offering the potential to prevent or halt a cycle of isolation/loneliness before it happens.

Study Weaknesses.

A quasi-experimental design, as used in this study, can decrease reliability and validity. Because the YAMI population is challenging to reach, primary data sources in this study do not give a complete depiction of the population, and have biases, noted in detail previously. In addition, attrition of study participants will affect results.

Suggestions for Future Studies

This study is distinctive in its focus on the young adult life stage. Many studies on mental health and this age group focus on the age of onset, but do not explore further. The USD research team recommends further studies on this population, ideally with YAMI who are isolated and not medicine or treatment compliant. Also recommended is an evaluation tool specifically created

for YAMI to assess recovery. Finally, the USD research team suggests a longitudinal study to annually assess and track the progression of YAMI involved in this program.

Budget

Impact More Expenses		
Item	**18 months**	**Annualized**
Personnel		
Executive Director	$52,500	$35,000
Outreach Coordinator	$30,000	$20,000
Administrative Assistant	$22,500	$15,000
Subtotal Personnel Costs	**$105,000**	**$70,000**
Fringe Benefits (10%)	$10,500	$7,000
Total Personned Costs	**$115,500**	**$77,000**
Operations		
Rent	$5,220	$3,480
Insurance	$18,000	$12,000
Utilities	$1,980	$1,320
Printing, Postage, Mailing	$180	$120
Mileage & Parking	$544	$362
Cell Phone	$2,160	$1,440
Trainings	$560	$560
Total Operations	**$28,644**	**$19,282**
Other Anticipated Expenses		
Social Marketing	$1,980	$1,320
Incentives	$765	$565
Evaluation Consultant	$2,340	$1,560
iPads	$1,900	$1,900
Total Other Anticipated Expenses	**$6,985**	**$5,345**
Total all Direct Expense	**$151,129**	**$101,627**
Indirect 15%	$17,325	$11,550
Total Program Expenses	**$168,454**	**$113,177**

Program Budget Justification

Impact More Expenses Justification	
Item	**Description**
Personnel	
Executive Director	**0.70 FTE -** The executive director will establish the advisory committee, identify local organizations and providers to assist with recruitment, will manage staff, and supervise the launch and ongoing efforts of the "we are more" campaign.
Outreach Coordinator	**0.5 FTE** - The outreach coordinator will focus on recruiting program participants, working closely with the executive director to establish partnerships and web-based outreach strategies, and recruiting participants who come to the program through the "we are more" campaign.
Administrative Assistant	**0.5 FTE** - The administrative assistant will assist with clerical and administrative tasks, support the program by answering phones, filing, social media updates and logistical implementation of the "we are more" campaign. This person will also be present during the administration of the evaluations to ensure clarity and ease stress of participants.
Fringe Benefits (10%)	10% is added to the total personnel expenses. Benefits include HMO health coverage, social security, unemployment insurance, and disability insurance.
Operations	
Rent	Given there will only be 2 FTEs (1 FTE and 2 half-time employees) rent was calculated as follows: 2 FTE x 145/month x 12 or 18 months.
Insurance	Includes Directors and Officers insurance, workers compensation, and general liability.
Utilities	Includes phone, fax, and internet lines as well as networking set up and maintenance. This equals out to $110 per month.
Printing, Postage, Mailing	The printing and mailing of training/program materials, and outreach mailings. This equals out to $10 per month. Justification for limited amount budgeted has to do with the programs design of reliance on virtual communication methods, rather than traditional hard-copy mailings.
Mileage & Parking	This covers travel expenses for the outreach coordinator when attending meetings and events for recruitment purposes. This equals out to $30.17 per month which includes $20 for parking fees and 20 miles at .51 a mile.
Cell Phone	$60 per month for both the executive director and outreach coordinator will be allotted to cover cell usage during work hours. Each will have her/his own phone and the $60 will be a supplement.

Trainings	These trainings will cover topics such as leadership and community organizing as detailed in the program narrative and work plan. Trainings will be held twice; one at month 3 and another at month 11, thus the total is the same for the annualized and 18 month columns. Cost includes the purchase of items such as easels, markers, and other tools.
Other Anticipated Expenses	
Social Marketing	The purchase of inexpensive ads on music websites, printing of posters/postcards/brochures, obtaining a QR code and maintaining campaign website www.we-are-more.com.
Incentives	This allows for $10 gift cards to retail establishments for an average of 10 trainees a year (4x in a 12 month period or 6x in an 18 month period).
Evaluation Consultant	To contract a local university to assist in evaluation of data collected throughout the study.
iPad	Two iPads, for the purpose of administering the evaluation tools throughout the study period.

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